

# Living with and Accepting AF, at 34 years of age

- A Patient's Perspective By Martin Harman



**“I intend to be in control of my life, not be controlled by AF!”**

I was just short of my 34<sup>th</sup> Birthday when I was diagnosed with AF in October 2006.

I have always been a fitness fanatic, but playing football one weekend I sustained a bad knee injury that required surgery. The day after my operation I began suffering from palpitations, excessive sweating, and dizzy spells. I felt like someone

was tightening a strap around my chest and I was short of breath. I thought nothing of it at the time and just assumed it was a side effect of the general anaesthetic.

Two days later and still having the symptoms I got up to make a cup of tea when it hit me. The palpitations, the sweating, the dizziness, the room started to spin

and I felt as if I was falling over. I could feel my heart thumping against my chest and I was very short of breath. After consulting my local GP who identified the AF from an ECG, I was admitted to hospital for 4 days whilst I underwent various tests to try and identify if any underlying cause was triggering the condition. Ultimately they found nothing. The cardiologist I saw believes the episode was possibly triggered by the general anaesthetic although I am still not convinced to this day as I have had 3 general anaesthetics previously without a problem.

**“I felt like my life had been taken away from me”**

I was eventually discharged and sent home (still in AF) and told, “See you in 3 months at the out patient clinic!” That was it, no information, no guidance, just an appointment for the anti-coagulation clinic. Thankfully, a staff nurse, simply out of her own kindness, found a BHF AF leaflet, but that was the only information I was given.

So the next 3 months I spent educating myself about AF; websites, chat groups and speaking to other sufferers.

The most difficult thing for me was coming to terms with what I had, the impact it was having on me and how this was affecting my life. I felt like my life had been taken away from me. I know that sounds dramatic, but at the time that is how it felt. Going from doing what you want, taking it for granted, to then not being able to do anything, is tough to come to terms with. For 3 months my life consisted of my house, with the occasional 10 minute walk around the village! I went through so many emotions, anger and frustration, looking for someone to blame, wondering why this happened to me! Did something go wrong? Was too much anaesthetic administered? Questions rolled over in my mind.

I tried all different medications, different strengths, different combinations and nothing was working. I remained in AF permanently and could not even walk up the stairs without my heart rate racing! I was unable to work and I couldn't even walk for longer than 10 minutes. It was a battle against both the physical impact on me, and the mental one. I really struggled to come to terms with how my life was, and it is easy to fall into the trap of thinking it will never get better, is this is how my life is going to be?

My wife, family and work colleagues were very supportive of me at this time and I do think that was essential to aiding my recovery. You often forget about the people who have to sit and watch what is happening to you and they can't do anything to help, other than just be there for you, but that was enough.

My GP was fantastic, extremely understanding and was always supportive when I went to see him. We worked together with different medications in order to find one that would ultimately work and finally we did.

Amiodarone eventually got my heart under control and after 3 months reverted me back to NSR! The side effects were a concern, so I came off Amiodarone and began to use Flecainide alongside a beta-blocker. I had intermittent AF episodes along with prolonged attacks of ectopic beats. I was a regular visitor to my A&E department at the local hospital. Typically though, by the time I got to hospital the episode had passed!

Gradually I become stronger, eventually returning to work full time and I slowly started to exercise again. By early 2008 I had managed to put on the weight I had lost, was exercising daily and felt like my old self. I still had episodes but only occasionally. So, in discussions with my GP, I decided that I would stop taking my medication. I wanted to know if my body needed the drugs to control the occasional attacks. How would I know unless I stopped taking them? As I am relatively low risk because of my age and overall health other than the AF, he agreed and helped me. Warfarin was first, then gradually over the next 3 months I came off all my medication. My symptoms are no worse, I still have the odd episode, but mine tend to be short, about 1 – 4 hours maximum and I get prolonged ectopic beats occasionally.

### **“Is this is how my life is going to be?”**

I have learned to understand the signs. I know what triggers my AF - it's the usual list you hear time after time, alcohol, caffeine - but I also suffer if I get overtired, or stressed. It doesn't mean I don't enjoy the occasional alcoholic drink or a few cups of coffee, but I have to be careful. I also make sure I am well hydrated drinking 2-3 litres of water a day. I found keeping a record of what I ate, drank and how I was feeling helped me notice the pattern and ultimately helped me to

live a near normal life! I understand not everyone is as fortunate as me and that's why I want to help AFA.

I am far more educated about AF than when I was diagnosed. Back in 2006, I had never even heard of AF! But it's amazing how much more I am still learning about the condition and how to live with it. AFA has been great and the patient day in October 2008 was excellent. I urge anyone reading this, or who has AF, to attend in 2009. I learnt more in 1 day than in the last two years.

For the future, well, I want to do whatever I can to raise awareness of this condition, despite rising numbers of patients, there is a lack of good, useful information. AFA is changing that and the more knowledge that people have, the better equipped they are to lead some kind of normal life. I believe that with better information, education and understanding at the time I was diagnosed, I would have coped better.

Two years on I am almost back to my normal self, no longer on medication, managing my condition and living a fairly normal life, with just the occasional setback on certain days. I am exercising daily and training to compete in a triathlon - all for the AFA charity of course!

I realise others may think “lucky you”, but that is one of the reasons I wanted to share my story. I appreciate that I am one of the more lucky ones, perhaps not as symptomatic as some AF sufferers. Maybe because I am young it is not so frequent and this may change as I get older, but for now, I intend to be in control of my life, not be controlled by AF! I want to share my experiences with people, particularly younger people, in order to try to help anybody out there who is going through what I went through, as I understand how difficult it is to live with and accept AF.